



BILLING CODE 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Services Administration (HRSA), Department of Health and Human Services (HHS).

ACTION: Notice of Meeting.

SUMMARY: In accordance with the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) will hold a public meeting.

DATES: Wednesday, May 9, 2018, from 9:30 a.m. to 5:00 p.m. Eastern Time (ET) and Thursday, May 10, 2018, from 9:30 a.m. to 1:00 p.m. ET.

ADDRESSES: The public may attend this meeting in person or via Webcast. While this meeting will be open to the public, advance registration is required. Please register online at <http://www.achdncmeetings.org/> by 12:00 p.m. ET on May 7, 2018.

The address for the meeting is 5600 Fishers Lane, Rockville, MD 20857. Non-U.S. citizens planning to attend in person will need to provide additional information to HRSA by Monday, April 30, 2018, 12 p.m. ET. To facilitate access to the building, please contact Ann Ferrero at the contact information listed below. Individuals who plan to attend and need special assistance, such as sign language interpretation or other reasonable accommodations, should notify Ms. Ferrero at least 10 days prior to the meeting.

The meeting will also be accessible via Webcast. Instructions on how to access the meeting via Webcast will be provided upon registration.

FOR FURTHER INFORMATION CONTACT: Anyone requesting information regarding the ACHDNC should contact Ann Ferrero, Maternal and Child Health Bureau (MCHB), HRSA, in one of three ways: 1) send a request to the following address: Ann Ferrero, MCHB, HRSA 5600 Fishers Lane, Room 18N100C, Rockville, MD 20857; 2) call 301-443-3999; or 3) send an email to AFerrero@hrsa.gov.

SUPPLEMENTARY INFORMATION: *Background:* The ACHDNC provides advice and recommendations to the Secretary of HHS on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing morbidity and mortality in newborns and children having, or at risk for, heritable disorders. In addition, ACHDNC's recommendations regarding inclusion of additional conditions and inherited disorders for screening are included in the Recommended Uniform Screening Panel (RUSP) following adoption by the Secretary. Conditions listed on the RUSP constitute part of the comprehensive preventive health guidelines supported by HRSA for infants and children under section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered health plans and health insurance issuers are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for screenings included in the HRSA-supported comprehensive guidelines for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

Agenda: The meeting agenda will include: (1) presentations and discussion on risk assessment in newborn screening; (2) presentation of educational tools for communicating newborn screening results; (3) presentations from states working toward timeliness goals in newborn screening; (4) an update on the status of newborn screening pilot studies for Guanidinoacetate Methyltransferase (GAMT) deficiency; (5) updates from the Laboratory Standards and Procedures workgroup; (6) updates from the Follow-up and Treatment workgroup; (7) updates

from the Education and Training workgroup; and (8) reviewing the process for assessing the public health impact of adding conditions to the RUSP.

There are no votes scheduled for this meeting. The final meeting agenda will be available two (2) days prior to the meeting on the Committee's website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>. Please note that agenda items and meeting times are subject to change as priorities dictate.

Public Participation: Members of the public will have the opportunity to provide comments, which are part of the official Committee record. To submit written comments or request time for an oral comment at the meeting, please register online by 12:00 p.m. ET on May 3, 2018, at <http://www.achdncmeetings.org/>. Oral comments will be honored in the order they are requested and may be limited as time allows. Individuals associated with groups or who plan to provide comments on similar topics may be asked to combine their comments and present them through a single representative. No audiovisual presentations are permitted. Written comments should identify the individual's name, address, email, telephone number, professional or organization affiliation, background or area of expertise (i.e., parent, family member, researcher, clinician, public health, etc.) and the topic/subject matter.

Amy P. McNulty,

Acting Director,

Division of the Executive Secretariat.

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